

SMALLER HAEMOPHILIA CENTRES PRESENTATION

INVERNESS

The Centre

1. From around November 1970 the Centre was located at the Raigmore Hospital, Perth Road, Inverness.¹ In 1978 the Centre was described by its Director as *'the smallest Centre in the UK'*.²
2. Perhaps unsurprisingly as the smallest centre, and alongside Aberdeen and Dundee,³ the Centre took its lead from the larger Scottish centres of Edinburgh and Glasgow. Edinburgh was formally the reference centre for Inverness.⁴

The Directors

3. In the early 1970s, Dr Iain Cook was the Director of the Centre until his death in 1982.⁵ Dr Cook attended UKHCDO meetings from 1968 onwards.⁶ From May 1975 to September 1977 Dr Cook was the Scottish representative at English Blood Transfusion Directors' meetings.⁷
4. Following Dr Cook's death, Dr Thomas G. Taylor became the Director. From around 1991 Dr Taylor was a member of the Factor VIII Working Party.⁸

¹ HSOC0022740, p. 4.

² CBLA0009239

³ See, for example, Dr Ludlam's comments at the August 1988 meeting of the Scottish Factor VIII Working Party: SBTS0000297_008.

⁴ §22.87 of PRSE0007002

⁵ HSOC0022904

⁶ For example, 1 October 1968 meeting of Haemophilia Centre Directors held at Oxford, which discussed the introduction of cards for haemophiliacs as well as an increasing workload for Centres following increased availability of cryoprecipitate and fresh frozen plasma: HCDO0001013. He also attended the 5 April 1971 meeting of the Haemophilia Centre Directors held at Oxford, where Dr Biggs gave a short summary of her report on jaundice and inhibitors in haemophilia A and B patients treated during 1969: HCDO0001014.

⁷ BPLL0004365

⁸ SBTS0000340_047; SBTS0000300_006. It appears that there was no specific attendance by any clinicians from the Centre at the Scottish and Northern Ireland Factor VIII Working Party meeting in the late 1980s. The membership of that group was made up of the Directors of Edinburgh, Glasgow and Belfast as well as members of the PRC and SNBTS: For example, SBTS0000297_008 and SBTS0000297_053

5. Dr William Murray was then the consultant haematologist at Raigmore Hospital from 1987 until 2010.⁹ Dr Craig then took over the haemophilia service.

Facilities and staffing at the Centre in 1970s and 1980s

6. The Inquiry presently has no witness evidence from the clinicians who worked at the Centre in the 1970s and 1980s. Therefore, there is no clear picture about the facilities and staffing at the Centre in the 1970s and 1980s.
7. The documents show that in around 1976 a second consultant joined Dr Cook.¹⁰ Dr Cook stated that he would be willing to assist in training of senior registrars in blood transfusions for the SBTS now that he had another consultant working with him.
8. One witness, who was diagnosed with haemophilia in 1980 at the Centre when he was 12, describes a lack of separate facilities for paediatric and adult haemophiliacs at the Centre: '*Children were dealt with together with adults at Raigmore as the haematology centre was essentially a tiny room.*'¹¹
9. Elizabeth Briggs and Katherine Adamson were listed as part of the haematology department at Raigmore during 1985.¹²
10. Dr Patrick Zentler-Munro, consultant physician, treated patients with HCV during the 1990s. Dr S. I. A. L. Mathieson was a consultant at Raigmore who specialised in the treatment of HIV.¹³
11. In 2000 Morag Kerr became a HCV nurse at Raigmore. She has provided a statement to the Inquiry.¹⁴

⁹ WITN3553001

¹⁰ SBTS0000087_075

¹¹ §5 of WITN2258001

¹² HIGH0000012

¹³ WITN2149006

¹⁴ WITN4189001

North of Scotland Blood Transfusion Service

12. The North of Scotland Blood Transfusion Service (“NSBTS”) was based at Raigmore hospital. There were close links between the Centre and the NSBTS, as Dr Cook was both the Director of the haemophilia centre as well as the Regional Director of the NSBTS. Dr Cook was Regional Director of NSBTS from 1960 to 1982.¹⁵ NSBTS was based at Raigmore hospital from April 1970 and, as at 1979, supplied blood and blood products to a population of around 224,000.¹⁶ Dr Cook described the existence of a ‘*very highly organised records system*’ which enabled him ‘*within a few hours, to “track down” the name(s) of any patients receiving whole blood, concentrated red cells, platelet concentrates, fresh frozen plasma, etc, or, secondly, blood products such as Factor VIII Concentrate...*’¹⁷

13. In 1983¹⁸ Dr William Whitrow took over as Regional Director of the NSBTS and held this role until 1993 when he was replaced by Dr George Galea. The relatively remote location of Inverness shaped the way the NSBTS was run. In the mid-1980s Dr Whitrow explained that the North of Scotland Region:

*‘covered some 10,000 square miles, being approximately half the total area of Scotland, but that the 250,000 population represented only some 5% of the population of Scotland. In view of the far flung nature of the areas of population, this caused a different approach to collection of blood from donors to that employed in other Regions of Scotland.’*¹⁹

14. Both Drs Cook and Whitrow sought to improve the facilities at the NSBTS. In February 1982 Dr Cook made a formal request for the extension of the Inverness Regional Transfusion Centre.²⁰ He noted that there was an ‘*increased clinical demand from blood alone since 1970*’. In December 1983 Dr Whitrow produced a case for the extension of the NSBTS on the basis that new laboratory facilities,

¹⁵ Page 18 of SBTS0000562. In 1983, after his death in 1982, Dr Cook’s family donated funds to the SNBTS and the interest on this sum was used to create a memorial lecture series. The first took place in Glasgow in 1984.

¹⁶ SCGV0000085_024

¹⁷ SBTS0000682_025

¹⁸ In July 1982 Dr Pauline Vosylius was listed as an Acting Consultant at the North of Scotland Blood Transfusion Service.

¹⁹ SCGV0000050_001. He also reported a drop in the numbers of donations between 1984 and 1985 which he wondered ‘*if the misunderstanding arising from some donors wrongly imagining that donating blood could give rise to AIDS disease, might be in some part to blame.*’

²⁰ SBTS0000136_047. See also: SBTS0000230_065

clerical and donor areas were required.²¹ Like his predecessor, Dr Whitrow noted that there had been a *'steady and progressive increase in workload in all sections of the Centre since 1970. A greater proportion of the whole blood is now processed to produce specialised blood products...Inverness has traditionally been to the fore in its programmes of manual plasmapheresis for anti-D immunoglobulin.'* In particular Dr Whitrow requested a purpose-built new blood processing area where hepatitis testing could take place.

15. By 1992/1993 approval was given for the creation of a new blood transfusion centre, which was a joint venture between the BTS and Raigmore Hospital's haematology department.²²

16. When Dr Whitrow retired from his role as Director of the NSBTS in 1992, Dr Murray, the Director of the Centre at that time, was asked to sign off on the job description for Dr Whitrow's replacement, showing continuing close links between the Centre and the NSBTS in the early 1990s.

Numbers of patients registered and numbers of patients treated by the Centre

17. The available documents show that in June 1973 Dr Cook had 16 haemophiliacs under his care.²³ The Penrose Inquiry found that as at 4 October 1976 there were 14 haemophilia patients at Inverness.²⁴ A document from 1978 suggests that 18 patients had received factor VIII and 1 patient had received cryoprecipitate.²⁵ In 1981 the number of haemophilia patients was said to be 16.²⁶

18. The available annual returns, set out below, reveal that commercial products were not used at the Centre and the treatment provided was almost exclusively NHS Edinburgh factor VIII and IX.

²¹ SCGV0000271_018

²² NHBT0002938

²³ SBTS0000309_040

²⁴ §19.62 of PRSE0007002

²⁵ SBTS0000310_027, with one of these patients also received factor VIII at Belford Hospital.

²⁶ SBTS0000306_017

19. The annual return from 1977 states that the Centre treated 19 haemophilia patients in that year. One patient had haemophilia B. No patients had factor VIII or IX antibodies. There were no deaths recorded. The only factor VIII used at the Centre was 144,780 units of Edinburgh factor VIII. Similarly, the only factor VIII used for those on home treatment was 35,270 units of Edinburgh factor VIII. It was noted on the annual return that the intention was to increase the number of patients on home treatment in the next five-year period due to the '*long distances...in a scattered community.*'²⁷
20. The annual return from 1978 states that the Centre treated 18 haemophilia A patients in that year, one of which had factor VIII antibodies.²⁸ There were no haemophilia B patients treated. Only Edinburgh factor VIII were used. No deaths were recorded that year. Two patients were noted to be on regular home therapy. No patients were noted to be jaundiced in 1978/1979. Dr Cook also completed the MRC Cryoprecipitate Working Party forms for this year.
21. The annual return from 1979 states that the Centre treated 20 haemophilia A patients and one patient with haemophilia B in that year.²⁹ Only Edinburgh factor VIII and IX were used. No deaths were recorded that year and no patients were listed as jaundiced in 1979/1980. Dr Cook also completed the MRC Cryoprecipitate Working Party forms for this year.
22. The annual return from 1980 states that the Centre treated 15 haemophilia A patients and one patient with haemophilia B in that year.³⁰ Only Edinburgh factor VIII and IX were used.
23. The annual return from 1981 states that the Centre treated 12 haemophilia A patients and one patient with haemophilia B in that year.³¹ Only Edinburgh factor VIII and IX were used.

²⁷ HCDO0002504

²⁸ HCDO0002505

²⁹ HCDO0002506

³⁰ HCDO0002507

³¹ HCDO0002508

24. The annual return for 1982 was not completed on the designated form due to the death of Dr Cook. Dr George Discombe³² wrote to Ms Spooner explaining this and that in Dr Taylor's absence (due to annual leave) he was trying to get information on product use.³³ The letter states that a preliminary search suggested that five haemophilia A patients were treated under the control of the laboratory and all of these five patients were on home treatment.³⁴ The only product used was Edinburgh factor VIII. This letter from Dr Discombe was followed up by Dr Withrow who explained that the records were '*far from complete*' but that '*when we get ourselves sorted out with a proper filming system... the statistics will again be accurate.*'
25. The annual return from 1983 states that the Centre treated 13 haemophilia A patients, one patient with von Willebrand's disease and one patient with haemophilia B in that year.³⁵ Only Edinburgh factor VIII and IX were used. Dr Taylor is listed as the Director and also completed the MRC Cryoprecipitate Working Party forms for this year.
26. The annual return from 1984 states that the Centre treated 16 haemophilia A patients and two patients with haemophilia B in that year.³⁶ Only Edinburgh factor VIII and IX were used.
27. The annual return from 1985 states that the Centre treated 10 haemophilia A patients and one patient with haemophilia B in that year.³⁷ Only Edinburgh factor VIII and IX products were used.
28. The annual return from 1986 states that the Centre treated around 16 haemophilia A patients and one patient with haemophilia B in that year.³⁸ Cryoprecipitate, DDAVP and Edinburgh factor VIII and IX products were used.

³² Locum consultant haematologist

³³ HCDO0002509

³⁴ This seems likely to be an underestimate. SBTS0000382_093 from 1982 suggests at least six patients.

³⁵ HCDO0002510

³⁶ HCDO0002511

³⁷ HCDO0002512

³⁸ HCDO0002513

29. The annual return from 1987 states that the Centre treated around 16 haemophilia A patients and one patient with haemophilia B in that year.³⁹ DDAVP, Edinburgh factor VIII and IX products were used.

Treatment policies and blood product usage

30. During the 1970s it appears that this small centre broadly followed the approach of other small Scottish centres. In 1973 Dr Cook stated that it was '*just not possible to undertake any research*' in relation to a new factor VIII concentrate because of the small number of haemophiliacs at the Centre. He stated '*these people are so scattered and one cannot obtain the required specimens the follow-up needed.*' He stated that Glasgow and Edinburgh would make decisions about the new product and that he would be '*interested to hear what is decided in due course.*'⁴⁰

31. Correspondence between Dr Cook and John Watt, Scientific Director of the SBTS' PFC, indicates that Dr Cook's preference was that '*the really severe haemophiliacs*' under his care should receive biweekly factor VIII: '*no doubt my plan is too ambitious at this stage but you will, I am sure, appreciate that these demanding patients and their relatives do like to know where they stand for the future.*'⁴¹

32. Letters written by Dr Cook in this period show fluctuating availability of blood products. In October 1975 Dr Cook highlighted that he had a shortfall of factor VIII and that '*inevitably we have had to return to making cryoprecipitate.*'⁴² In November of the same year there were continuing discussions about the Centre having enough factor VIII to treat its severe haemophiliacs.⁴³

33. However, by December 1975 Dr Cook stated that he was receiving '*a lion's share*' of factor VIII over the last three months and that this was unfair to other Centres,

³⁹ HCDO0002513

⁴⁰ SBTS0000309_040

⁴¹ SBTS0000309_159

⁴² SBTS0000309_163

⁴³ SBTS0000309_173

such as Dundee.⁴⁴ He made a decision to return to using cryoprecipitate *‘in all cases attending this Centre or Raigmore Hospital, as far as possible.’* He decided to restrict factor VIII to two named severe haemophiliacs. It appears the reason for this decision was to *‘restore the balance of fair-play between the smaller Centres.’* In his view: *‘it would certainly seem that the present allocation to Inverness is over-generous and over-estimated.’*

34. In October 1977 Dr Cook raised concerns about availability of PPS⁴⁵ and factor VIII.⁴⁶ In relation to the former, he stated that this was due to *‘pyrogenicity problems’* causing a disruption to supply. This meant that he had written to anaesthetists and surgeons in *‘out-lying’* hospitals to say that he could not guarantee supply. He was reliant on a delivery of dried plasma coming *‘on the PFC vehicle’* but he could not *‘see the clinicians being very keen to use [the] same.’* He was concerned that a lack of supply of PFC product would lead to use of commercial products: *‘My main fear is that the clinicians, through the pharmacists, will purchase some of the commercial preparations regardless of any comments from myself.’*

35. In relation to factor VIII, Dr Cook described the supply situation as *‘even more worrying’*. Dr Cook called for more dialogue, in the form of a Directors’ meeting, in order to address the issue of clinical demand.⁴⁷ In the absence of access to factor VIII, he relied on cryoprecipitate:

‘General Jeffrey⁴⁸ was adamant that smaller Centres must no longer make cryoprecipitate and we have certainly not made any for about 18 months. I see no option but to produce some cryo now to bridge the gap between October/November supplies.’

36. On 14 January 1977 John Watt’s position was that there was *‘something serious happening about usage of factor VIII in Inverness.’* He stated that the *‘North Region has more haemophiliacs on home therapy proportionately than elsewhere’*

⁴⁴ SBTS0000309_186

⁴⁵ Plasma protein solution

⁴⁶ SBTS0000088_154

⁴⁷ John Watt’s response to some of these issues can be found at: SBTS0000100_077

⁴⁸ Major-General H. C. Jeffrey, National Director of SNBTS

and he would expect this to lead to a reduction of AHF usage.⁴⁹ Dr Cook produced a robust response on 20 January 1977 setting out the specific needs of his patients.⁵⁰

37. In 1978 18 patients were listed as receiving factor VIII, with one patient receiving cryoprecipitate.⁵¹

38. In July 1979 there were three haemophiliacs at the Centre on home treatment.⁵² Dr Cook described it as '*embarrassing*' that he had an excess of factor VIII stock for the last two to three months. He requested that no further supplies be sent while they use up the spare stock. The Inquiry has received witness evidence from patients being taught to use home treatment in the 1980s.

39. In February 1981 Dr Cook again offered to reduce his factor VIII allocation. He stated: '*I will be the first to shout if I think that my 16 haemophiliac patients are being inadequately treated in the long term.*'⁵³ On 3 March 1982 he wrote to the Scientific Director of the SNBTS offering two months' of factor VIII to another centre or to do without for two months '*if this is of any help*'.⁵⁴

40. The Penrose Inquiry concluded that from 1981 to 1985 '*almost no cryoprecipitate*' was used.⁵⁵

41. In July 1988 Dr Thomas provided the Highland Health Board with the Centre's factor VIII usage.⁵⁶ He cautioned against putting too much weight on the figures as the Centre's small number of patients meant that '*one or two small bleeds in one patient can give the impression that [the] overall issues of Factor VIII are increasing.*' Dr Thomas' view was that the Centre's factor VIII use over the last five years, i.e. from 1983 to 1988, was '*fairly steady.*'

⁴⁹ SBTS0000304_010

⁵⁰ SBTS0000304_174

⁵¹ SBTS0000310_027

⁵² PRSE0000581

⁵³ SBTS0000306_017

⁵⁴ SBTS0001486_008

⁵⁵ §12.157 of PRSE0007002

⁵⁶ SCGV0000110_054

42. In relation to factor IX, there is less documentary evidence available. The documents, however, suggest that there was a supply problem in 1987. Dr Cash⁵⁷ wrote to Dr Whitrow in August 1987 stating there was *'some difficulty'* with factor IX supply.⁵⁸ The reason given for this was increased usage as a result of a growth in the number of haemophilia A patients with inhibitors. Dr Cash stated: *'it is important that we don't start a panic – for that would be quite inappropriate and indeed the problem is currently not that severe'*. The solution proposed was for Dr Whitrow to liaise closely with local colleagues to ensure that *'the supply of PFC DEFIX for haemophilia B patients is always secure and that if they run short for inhibitor patients then they obtain commercial supplies.'*

43. The Penrose Inquiry⁵⁹ found that only SNBTS products were used at the Centre from 1974 onwards. Dr Cook in August 1979, in response to a letter from the director of Speywood, stated that the SBTS has its own *'largely self-supporting'* Protein Fractionation Centre. Dr Cook stated that he would keep this commercial product in mind *'if there are any unusual demands e.g. surgery in Haemophilia, but at present our stocks are more than adequate.'*⁶⁰

44. In 1982 - the year where there is no completed UKHCDO annual return - 615 bottles of NHS factor VIII were distributed to patients at the Centre.⁶¹ Minutes of the February 1989 Factor VIII Working Party demonstrate zero commercial factor VIII use at Inverness in 1987 and 1988.⁶² Coagulation factor usage surveys from 1988 and 1989 also show only PFC factor VIII being used.⁶³

45. In relation to DDAVP, the Penrose Inquiry found that Inverness used *'varying amounts (between 4 and 108 international units) beginning in 1987 but used none*

⁵⁷ National Medical Director of the Scottish National Blood Transfusion Service

⁵⁸ SBTS0000249_107

⁵⁹ ARCH0003312; §12.14 of PRSE0007002

⁶⁰ IPSN0000324_015

⁶¹ SBTS0000382_093. A total of 133,720 units were distributed from the Centre, excluding returns to Edinburgh.

⁶² SBTS0000298_005

⁶³ See for example, SBTS0000311_069 and SBTS0000311_074

*before that date.*⁶⁴ However, the annual return from 1986 demonstrates use of DDAVP in 1986.⁶⁵

46. The Penrose Inquiry found that heat-treated blood product was supplied to the Centre early in December 1984.⁶⁶

47. Dr Taylor, as Director of the Centre at the relevant time, was copied into Dr Ludlam's correspondence with SBTS requesting supply of high purity factor VIII for Scotland and Northern Ireland in late 1990.⁶⁷ It appears that the Centre took no leading position on this issue and followed the approach of Dr Ludlam.

48. In November and December 1992 Dr Taylor wrote to the parents of a haemophiliac child asking to give consent to the trial of a high purity product.⁶⁸

Knowledge of risk of hepatitis and response to risk

49. There is little direct evidence about Dr Cook's or Dr Taylor's knowledge of non-A non-B hepatitis. However, they attended a number of UKHCDO and Scottish haemophilia directors meetings where there was discussion about hepatitis, and latterly non-A non-B hepatitis.

50. Dr Cook regularly attended UKHCDO meetings, including the meeting on 18 September 1975 meeting where there was discussion on the relationship between factor VIII pool size and risk of hepatitis infection.⁶⁹

51. In his role as Director of NSBTS Dr Cook was part of the decision making about screening of blood donors for hepatitis in the early 1970s. In particular, it appears that Dr Cook was concerned about the spread of hepatitis B.

⁶⁴ §12.183 of PRSE0007002

⁶⁵ HCDO0002513

⁶⁶ §12.188 of PRSE0007002

⁶⁷ For example, SBTS0000706_224

⁶⁸ WITN2188002 and WITN2258007

⁶⁹ OXUH0003735

52. On 16 October 1970 Dr Cook wrote to the Scottish Home and Health Department in relation to the introduction of hepatitis screening for ‘*Antigen H.A.A.*’ He proposed to start ‘*total screening of all blood donors*’ for this antigen.⁷⁰ As of December 1970, Dr Cook had not found any donors with either hepatitis associated antigen or antibody.⁷¹ In relation to patients he states ‘*it is difficult to justify ethically two laboratories in the same laboratory block undertaking these tests. I have an open mind to the solution to this problem and it merits further discussion*’.⁷² In 1971 the testing technique was changed after there was a failure to find any cases of hepatitis with the antibody. It was noted that this region had a ‘*low*’ incidence rate of serum hepatitis.⁷³ He had found four cases with hepatitis-associated antigen in approximately 5,400 donors.

53. On 30 July 1971 Dr Cook informed the Scottish Home and Health Department that they had found ‘*our first example of Antibody to Australia Antigen in an ex-Raigmore Hospital Nurse*’.⁷⁴ In September 1971 Dr Cook wrote again following a ‘*recent fatal case of hepatitis in Raigmore*.’ The letter demonstrates his strength of feeling in relation to the protection of clinicians: ‘*I feel it is essential that some action is taken as soon as possible to prepare material which might be used to try to protect Medical or Medical Nursing staff and even more so, one’s own staff in the future*’. Dr Cook called for an expert report to be drafted and concluded: ‘*I feel Scotland should go ahead on its own*’.⁷⁵

54. From around 1975 Dr Cook was said to be testing ‘*every specimen*’ for hepatitis B.⁷⁶ In correspondence to Dr Cash, Dr Cook wrote:

‘I feel that it is my duty to see that Hepatitis B Surface Antigen is excluded from the Transfusion Centre, not only in the interests of the staff at risk, but from the remote possibility of contamination of blood or blood products.’

⁷⁰ SCGV0000279_038

⁷¹ SCGV0000279_015

⁷² SCGV0000279_015

⁷³ SCGV0000204_165

⁷⁴ SCGV0000204_153

⁷⁵ SCGV0000206_100. It appears that the infection was, in fact, not a ‘*virus B infection*’:
SCGV0000206_099

⁷⁶ SBTS0000100_074

55. In response to that correspondence, Dr Cash confirmed that he had not adopted the same policy *'primarily because I have been extremely worried of the consequences that would flow from such an exercise.'* Dr Cash referred to *'the prospect of chaos in the Health Service. There are certainly extremes of opinion: those who do not wish to know and those who believe it is essential to know whether a patient is HBsAg positive.'* Dr Cash stated that *'many who would argue strongly that it would be an unacceptable use of scarce resources.'* He places this costs at an extra £40,000 per annum for the cost of such testing. He concluded:

'I must confess that at the moment, having not yet solved the problems that have inevitably emerged from the consequences of labelling our donors⁷⁷ HBsAg positive, I am reluctant to add to our difficulties by instituting the screening of all patients. Nevertheless, I would be very happy to discuss this matter with the group as part of our deliberations on hepatitis testing.'

56. As at January 1978 Dr Cook stated that there were *'no clinical cases of hepatitis amongst our haemophiliacs'* and that he *'was not aware of any of the present 16 individuals developing a positive result for HBsAg in 1977.'*⁷⁸

57. In May 1986 Dr Whitrow of the NSBTS wrote to the SNBTS's Dr Cuthbertson that *'there is no clear cut policy in this hugely sparsely populated region'* on the HBV testing or treatment.⁷⁹

Knowledge of risk of AIDS and response to risk

58. Dr Taylor attended the meeting of Directors of SNBTS and Haemophilia Directors on 21 January 1983. It appears this was Dr Taylor's first meeting of this nature. At this meeting Dr Cash drew attention to recent articles in the United States, *the Observer* and *the Lancet* about AIDS, and circulated the extract from CDC.⁸⁰

59. Dr Taylor attended the 1 February 1984 meeting where AIDS was again discussed and Dr Ludlam and Dr Hann advocated the use of cryoprecipitate in children due to the *'new danger of AIDS.'*⁸¹ He also attended UK-wide meetings, such as the

⁷⁷ Emphasis in the original

⁷⁸ SBTS0000381_097

⁷⁹ SBTS0000418_191

⁸⁰ PRSE0001736

⁸¹ PRSE0001556

meeting at Cardiff on 27 September 1984, where Dr Craske produced a report on AIDS.⁸²

Arrangements for testing patients for HTLV III and informing them of their diagnosis

60. During his evidence to the Penrose Inquiry, Professor Ludlam stated he would have sent out invitations to the east coast haemophilia centres, including Inverness, to attend a group meeting about AIDS held at Edinburgh on 19 December 1984.⁸³ However, this Inquiry has seen no evidence to date that any Inverness patients attended that meeting.

61. On 12 February 1985 Dr Taylor signed a template letter to the Centre's haemophilia patients and their parents about AIDS.⁸⁴ The letter refers to the:

'considerable disquiet among people with haemophilia throughout the country, about the subject of AIDS and we have had several enquiries from patients. Reports in the press and on television are often biased and may be misleading. For this reason I am enclosing some note[s] which we have compiled in the hope that we can answer the questions most commonly asked. It is simply a Summary of what we know at present about this disorder, together with a few points of advice on how to minimise the risk and brief details of the steps we are taking to combat the disorder.'

62. The letter invited patients to contact the Centre, either by telephone or by appointment, to address any outstanding questions. This template letter is not addressed to any particular patient and it is unclear if this letter was sent out to patients and, if so, when it was sent.

63. On the same date, 12 February 1985, there is a letter from Dr Adamson to an unknown person stating that *'because of the recent problems with AIDS, we are now producing new types of Coagulation Factors. Before this can be issued, we*

⁸² PRSE0003659

⁸³ §33.393 of PRSE0007002

⁸⁴ HIGH0000011

*need to do a blood test on each of our patients.*⁸⁵ The recipient of the letter is asked to telephone the Centre to arrange to have the blood test performed.

64. On 17 May 1985 Dr Pettigrew at the Royal Hospital for Sick Children, Glasgow, wrote to Dr Taylor, in confidence, about a young boy who had formerly been treated at Glasgow.⁸⁶ She informed Dr Taylor that Dr Follett of Ruchill had recently looked at stored samples at Glasgow – *‘these samples had been sent for HBs Ag analysis’* – and found that some of the Glasgow patients were HTLV III positive. Dr Pettigrew stated that she was informing Dr Taylor of this so that he *‘could arrange for appropriate measures to be taken.’* From the evidence available, it is unclear if stored samples were also held at Inverness.

65. The Inquiry has received witness evidence from the patient Dr Pettigrew wrote to Dr Taylor about. That witness recalls that Drs Taylor and Murray told his parents of his HIV infection when he was around 14 years old, i.e. in around 1987-1988.⁸⁷ His medical records suggest that *‘AIDS literature’* was sent to his mother in 1987 and that he was tested for HIV on 30 June 1987, although no test result is provided within that record.⁸⁸ The witness states that when his parents asked why they had not been told of his HIV infection earlier: *‘the doctors said that it was not hospital policy to tell patients.’*⁸⁹

66. On 22 May 1989 the General Secretary of the Haemophilia Society, David Watters, wrote to Dr Rizza of the Oxford Haemophilia Centre stating that he had *‘learned recently that patients with haemophilia attending Raigmore Hospital in Inverness and Aberdeen Royal Infirmary are not necessarily being advised [of] their HIV status.’*⁹⁰ The letter states that this issue had come *‘to light recently when a boy of 14 was suddenly told of his HIV antibody status – his parents having assumed, and the lack of any information to the contrary, that he was*

⁸⁵ HIGH0000012

⁸⁶ GMCO0001690_055

⁸⁷ §4 and §6 of WITN2149001

⁸⁸ WITN2149005

⁸⁹ §6 of WITN2149001. It is not clear from the witness evidence when this was said and by which doctor(s).

⁹⁰ LOTH0000006_028

negative.' It is unclear whether this relates to the circumstances described directly above but it may do.

67. On 7 January 1986 Dr Ludlum at Edinburgh wrote to Dr Taylor asking for information about whether any Inverness patients had seroconverted since the introduction of heat-treated blood products.⁹¹ The topic was to be discussed at an upcoming March 1986 meeting of the Directors.

68. Some witnesses have told the Inquiry that while their medical records demonstrate that they underwent tests for HIV, they were not told at the time that they were being tested.⁹²

69. In September 1988 the GMC produced a document titled '*HIV infection and AIDS: the Ethical Considerations*'. Dr McClure⁹³ wrote to the GMC objecting to that document and felt that AIDS '*should not be treated differently to any other disease*'. He referred to taking blood for other conditions and '*never had sought patient consent or explained the catastrophic social consequences if a test were to prove to be positive.*'⁹⁴ Dr Taylor, on 20 October 1988, wrote in support of Dr McClure's letter stating: '*Our department would give the strongest possible support to the views expressed by Dr McClure in his letter... we feel it inappropriate, unethical and illogical that we have to seek patient consent before testing for HIV.*'⁹⁵

Numbers infected with HIV

70. Dr Christopher Lush, Director of the Centre in 2011, informed the Penrose Inquiry that no haemophilia patients were considered to have been infected with HIV as a result of treatment at Inverness.⁹⁶

⁹¹ HIGH0000023

⁹² See for example, §20 of WITN2258001 and WITN2258013. Although, compare the evidence of his brother who stated that he was aware of having an HIV test in around 1984: §22 of WITN2995001.

⁹³ J. P. McClure was the honorary secretary of the Ayrshire and Arran Health Board.

⁹⁴ HIGH0000020

⁹⁵ HIGH0000020

⁹⁶ PRSE0007002

71. In the Penrose Inquiry's final report a total of two patients at Inverness, of the 73 patients tested in Scotland, were reported to be HIV positive.⁹⁷ This is consistent with the provisional UKHCDO data received by this Inquiry.⁹⁸

Treatment arrangements for HCV patients

72. Some infected haemophiliacs have told the Inquiry that they were informed of their diagnoses with HCV at routine appointments.⁹⁹ Those infected with HCV give evidence about the challenging side effects caused by anti-retroviral treatment.

Numbers infected with HCV

73. According to the Penrose Inquiry, as at 2011, there were 26 living patients who were infected with HCV at Inverness.¹⁰⁰

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⁹⁷ PRSE0007002

⁹⁸ INQY0000250

⁹⁹ For example, §2 of WITN2275001

¹⁰⁰ PRSE0007002